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An investigation of patients' motivations for their participation in genetics-related research

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ABSTRACT

Design: Qualitative interview study.

Participants: Fifty-nine patients with a family history of cancer who attend a regional cancer genetics clinic in the UK were interviewed about their current and previous research experiences.

Findings: Interviewees gave a range of explanations for research participation. These were categorised as (a) social—research participation benefits the wider society by progressing science and improving treatment for everyone; (b) familial—research participation may improve healthcare and benefit current or future generations of the participant's family; and (c) personal—research participation provides therapeutic or non-therapeutic benefits for oneself.

Conclusions: We discuss the distinction drawn between motives for research participation focused upon self (personal) and others (familial/social), and observe that personal, social and familial motives can be seen as interdependent. For example, research participation that is undertaken to benefit others, particularly relatives, may also offer a number of personal benefits for self, such as enabling participants to feel that they have discharged their social or familial obligations. We argue for the need to move away from simple, static, individualised notions of research participation to a more complex, dynamic and inherently social account.

The assumption that research participation is motivated by altruism—helping others—rather than undertaken for personal gain is widespread,¹ particularly when it comes to research that involves the donation of tissue² or blood/DNA samples.^{3–4}

Altruism and trust lie at the heart of research on human subjects. Altruistic individuals volunteer for research because they trust that their participation will contribute to improved health for others and that researchers will minimize risks to participants. (p873)¹

Although, as this recent consensus statement on clinical trial demonstrates, this focus on altruism is not confined to research involving human tissue samples, it might be speculated that altruism may feature to a greater extent in discussions of clinical genetics-related research, primarily because this research will, by definition, have a higher likelihood of benefiting a predefined group of people in addition to the participants—their biological kin. Looking more broadly, it has been observed that the positioning of altruism as the primary motivator of research participation in the UK may have arisen as a result of public discussions about the unconsented use of tissue/body parts in research²

and also in response to the seemingly exponential growth in the number of initiatives to create community-based DNA/tissue sample collections (eg, UK Biobank, MRC sample collections) in recent years.^{3–4} The scandal over retained organs (and subsequent public inquiries) and the creation of large-scale sample collections have resulted in the development of legislation (in the UK, the Human Tissue Act 2004) and a number of UK guidelines^{5–6} for the regulation and oversight⁷ of medical research involving human subjects/tissue samples. As Busby notes,⁴ these characterise research samples/donations as altruistic gifts, this treatment being in line with the common law in the UK.

Tutton⁸ argues that the current turn to altruism to account for participation in biobanking projects is influenced by Titmuss's definitions of altruism, which he developed in his comparative analysis of blood donation in the UK and the USA.⁸ In this, Titmuss conceptualises voluntary and unfettered donations as “free human gifts”, in which

[T]here are no tangible immediate rewards, monetary or non-monetary: there are no penalties; and donors know that their gifts are for unnamed strangers without distinction of age, sex, medical illness, income, class, religion or ethnic group. (p385)

Titmuss does, however, problematise overly simplistic notions of altruistic donation by pointing out that it involves both an awareness of need and an expectation of reciprocity. According to Titmuss,⁸ voluntary blood donation is a form of reciprocal altruism; it is a gift that is accompanied by the expectation that it will be reciprocated if, and when, necessary. Titmuss does not see reciprocal altruism as solely future-oriented, for he cites research that suggests that some people donate blood primarily to repay a donation that has been received by someone they know. Altruistic donation is thus characterised as a cyclical, or recursive, process that repays past donations and carries expectations of future returns for oneself or one's friends or family. Thus, Titmuss acknowledges that altruistic donation may involve a degree of self-interest.

Titmuss's analysis hints at the complexity of individuals' motives underlying voluntary blood donation, and this is reinforced by the findings of empirical studies of participation in genetics research, which suggest that, although individuals frequently describe their research participation as motivated by altruism,^{9–10} they are also driven by the anticipation of personal gain.¹¹ Certainly, as far as other types of clinical research are concerned

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there may be a number of obvious tangible benefits for research participants.¹² For example, there is a high probability that at least a proportion of participants will get clinical benefit from taking part in research that compares new with established therapies and this is often identified as one motive for participation in randomised clinical trials.¹³ Non-therapeutic research (such as (genetic) epidemiological or psychological research) may nevertheless have indirect or incidental clinical benefits, for there is a possibility that participants may obtain a result that has diagnostic consequences.¹⁴ Furthermore, although many research projects (eg, social science or epidemiological studies) may not appear to carry any clinical benefits for research participants, this does not mean that participation in research of this type is devoid of benefit per se, because the act of participation itself may either generate positive feelings about oneself or an enhanced self-image. Indeed, a recent study suggests that many participants were very positive about calling research donations “gifts”, arguing that naming this activity in this way made them feel good about themselves.² In other words, in addition to the clinical (and, in some cases, economic) benefits that are associated with some types of research participation, there may be internalised, self-regarding or emotional rewards.

While research may directly or indirectly benefit participants, this should not detract from the fact that many individuals say they are motivated by altruism and take part in research primarily to help others. For example, in their study of participation in genetic testing research protocols, Geller and colleagues observed that nearly 40% of participants stated that they became involved to help researchers rather than for any personal benefit, that is, to obtain a DNA test for themselves.⁹ A recent Australasian study of the genetics of endometriosis similarly reports that participants describe themselves as motivated by a desire to contribute to scientific knowledge and raise community awareness about the disease rather than personal gain.¹⁰ Indeed, the idea that research participation may benefit the wider community is frequently cited as a reason for participation in genetic epidemiological research. Haines and Whong-Barr¹⁵ and Hoeyer¹⁶ describe how donors to population biobanks in Cumbria (north-western England) and northern Sweden described their decision to contribute tissue samples as influenced by the desire to help research and to benefit society and future patients, including family members. However, these expressions of altruism were frequently qualified by interviewees, who commented that their willingness to participate had been influenced by the fact that the samples they donated would normally be destroyed (umbilical cord blood and tissue samples) or were interpreted as routine procedures (blood samples)¹⁵ or perceived as of “no consequence”.¹⁶ In other words, interviewees were willing to participate in these projects, at least in part, because they were not required to do much in order to do so.

The idea that research participation may be influenced by perceptions of the effort involved is discussed by Haines and Whong-Barr,¹⁵ who describe “different levels of participation” in the Cumbrian study. They note that while a large proportion of those approached were happy to donate tissue samples and thus take part, at least in a partial way, a much smaller percentage could be regarded as full participants—that is, they donated tissue samples and completed questionnaires containing personal information about their health and lifestyle. They contend that these different levels of participation map onto “styles of participation”, a more generalisable scheme that incorporates underlying motives and includes: *active participants*, who are

keen to contribute, *cost-benefit participants*, who weigh up the costs to self versus benefits to others, *passive participants*, who participate because participation does not involve much in the way of perceived risks or effort and, finally, *reluctant participants*, who are persuaded to take part by researchers/others.¹⁵

THE NATURE OF ALTRUISM?

The foregoing discussion highlights the fact that research is not a homogeneous activity, but involves different procedures and risks and, as a consequence, very different participatory experiences. Indeed, even within the broad categories of therapeutic and non-therapeutic research there are important differences between studies, involving greater or lesser risks and benefits and more or less effort from participants. For example, some research projects may involve daily or invasive and risky procedures (randomised drug trials), whereas others may entail a one-off donation of blood or non-invasive annual screening tests (genetic epidemiological research or screening research). These observations suggest that individuals may draw upon notions of altruism (or personal benefit) to different degrees and in different ways when accounting for their decision to take part in different types of research. It can be speculated that individuals may be more willing to be “altruistic” when (a) they personally have little to lose from research participation¹⁵ because it involves little effort^{15–17} or few risks (eg, anonymised epidemiological research) or there are no therapeutic options available to them even though the effort required and risks may be high (eg, non-therapeutic phase I trials) or (b) when the benefits of participation for self and others are closely allied despite the (increased) risks and/or effort (eg, therapeutic or molecular genetics research). In an effort to explore some of these issues, we undertook a series of semi-structured interviews with patients who had been involved in therapeutic and/or non-therapeutic research projects in a cancer genetics clinic in the south of England.

The overall aim of this qualitative interview study was to investigate lay and professional perceptions of the activities that take place in the cancer genetics clinic.¹⁸ In addition to healthcare professionals, researchers and other stakeholders, the study included three groups of patients who had been involved in different types of research projects. This paper looks at the ways in which these patients framed their motivations for research participation and argues that we need to move away from simple, static, individualised notions of research participation to a more complex, dynamic and inherently social account.

THE RESEARCH SETTING

Cancer genetics is a highly research-active subspecialty; many clinics in the UK were set up in the early 1990s to ascertain patients for molecular genetics studies, and this research legacy lives on today. Southampton (a regional genetics service covering a population of 3 million) was an ideal site to base our study, as it is one of the more active research centres in the UK, hosting a number of local, national and international research projects. For the purpose of our study these were classified as clinical, molecular, epidemiological, psychosocial and research registers.

Clinical research

This research involves studies that have a potential therapeutic benefit for participants, including (a) screening or surveillance studies, such as UKFOCSS (UK Familial Ovarian Cancer

Screening Study), an observational study of blood serum testing plus an annual transvaginal ultrasound; and MARIBS (Magnetic Resonance Imaging for Breast Screening), involving annual MRI or mammograms plus a blood sample at the end of the project and questionnaires before and after each screen; and (b) chemoprevention drug trials, such as CAPP2 (Colorectal Adenoma/carcinoma Prevention Programme), using aspirin and digestion-resistant starch, IBIS1 (International Breast Cancer Intervention Study), using tamoxifen; or RAZOR (Raloxifene and Zoladex Research Study), all of which involve taking drugs or placebo in addition to dietary interventions (CAPP2) and bodily surveillance (CAPP2, IBIS1, RAZOR).

Molecular or DNA-based research

This research may provide a diagnostic genetic test result, as in the Familial Breast Cancer Study (the “BRCA3” study) (in which *BRCA1* and *BRCA2* mutation testing was undertaken—in the early stages, before such testing was widely available as a clinical service) or searching for mutations in rare cancer syndromes (eg, Gorlin and Peutz-Jeghers syndromes).

Epidemiological studies

These comprise non-therapeutic research that requires few, if any, physical interventions or procedures and include, for example, EMBRACE (Epidemiological Study of Familial Breast Cancer), involving questionnaires and a blood sample, and POSH (Prospective Study of Outcomes in Sporadic Versus Hereditary Breast Cancer), an observational study of treatment choices and outcomes of young breast cancer patients.

Psychosocial studies

These comprise non-therapeutic research such as qualitative interview studies (eg, the psychological impact of VHL), questionnaires or quality-of-life evaluations.

Research databases

These were set up as a resource for epidemiological studies, and thus membership indicates a willingness to take part in future research projects (British Familial Cancer Record and/or the UK Coordinating Committee for Cancer Research’s Familial Ovarian Cancer Register).

Focusing our research in this particular clinic, therefore, offered us the ideal opportunity to consider and reflect upon individuals’ accounts of their research participation in a wide range of research studies. Moreover, recruiting our sample from a single clinic facilitated the data collection and also enabled us to keep population and other variables constant in our sample.

METHODS

Recruitment

Ethics approval was obtained from Scotland’s Multi Research Ethics Committee A in November 2005. Potential participants who had attended the Wessex regional genetics service during the previous 12 years to discuss their personal or family history of cancer were approached with an invitation to participate. Patients were purposively sampled from clinic lists and the British Familial Cancer Record to include roughly equal groups of interviewees who had previously participated in molecular DNA-based research, clinical research, and epidemiological and psychosocial research (table 1).

Data collection and analysis

In-depth face-to-face interviews were carried out by SC and GC from March 2006 to March 2007 at a location of the participant’s choice (home, workplace or genetics clinic). These lasted for 40 to 90 minutes and were tape-recorded, with consent. Interviews began with a number of demographic questions and then interviewees were asked to provide a narrative account of their involvement with the genetics clinic and research projects they had previously participated in. Discussion about a range of clinical and research activities was subsequently prompted and interviewees’ responses were explored to establish: their motivations for research participation and individuals’ motivations in general, their perceptions of clinic activities, the differences and similarities between research and clinical practice and their views about the ethical conduct of research.

One interview was conducted with two related participants, so only 58 interviews were carried out. Transcripts were read through many times by different team members to identify recurrent themes within and between participants’ accounts. The method of constant comparison¹⁹ was used to develop a coding frame. The codes emerging from the analysis were discussed and verified by members of the research team. Data were managed using QSR N6.

RESULTS

Participants

One hundred and forty-four patients with a high risk of cancer were sent an invitation pack containing an information sheet and an expression-of-interest form to be returned to the research team. Fifty-nine (41%)—12 men and 47 women—agreed to be interviewed. The 59 interviewees were aged between 29 and 83 years (mean 50 years). Fifty (85%) of the interviewees had children, and 34 of these (68%) had male and 44 (88%) female children. Twenty-one interviewees (36%) for whom data are available had further or higher educational qualifications.

Thirty-seven (63%) of the interviewees had previously had cancer and 42 (71%) had undergone DNA testing. Thirty-five (59%) had a family history of breast or ovarian cancer, 9 (15%) bowel or colon cancer and 15 (25%) other types of cancer or cancer syndromes.

According to their clinical notes, the interviewees had participated in 1 to 6 research studies (mode 3) (see table 1), including this one. Of the 52 interviewees who had previously participated in research, one was recruited to a molecular genetics study in 1984 and the remainder had been recruited between 1995 and 2006. Forty-seven interviewees had participated in studies involving interventions that had potential therapeutic benefits, including 22 who had taken part in screening or chemoprevention studies (hereafter referred to as “CR”) and 25 in molecular and DNA-based research (“DNA”), 29 had taken part in non-therapeutic epidemiological (“EPI”) or psychosocial studies (“PS”) and 31 interviewees were members of research databases (“REG”).

Accounting for research participation

Analysis revealed that our interviewees framed their previous, or hypothetical, motivations for research participation in three ways—personal, social and familial—and that these framings were frequently juxtaposed within the interviews, so that, in practice, it was difficult to characterise interviewees’ accounts as either self- or other-oriented. However, although, the motives underlying research participation coexist within interviewees’ accounts, they will be presented separately for the purpose of analysis.

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Table 1 Previous research participation of interviewees

Type of research study	Number
Therapeutic research	
Molecular or DNA research	25
Familial Breast Cancer Study	11
Molecular research for rare diseases	9
Other (<i>BRCA1</i> and 2)	5
Chemoprevention trial	9
CAPP2	6
RAZOR	1
IBIS1	2
Screening study	17
MARIBS	7
UKFOCCS	8
Other	2
Non-therapeutic research	
Epidemiological	18
POSH	2
EMBRACE	12
Other	4
Psychosocial	11
Genetic counselling study	4
Von Hippel-Lindau interview study	4
Other	3
Research database	31
BFCR	29
UKCCCR Familial Ovarian Register	2

BFCR, British Familial Cancer Record; CAPP2, Colorectal Adenoma/Carcinoma Prevention Programme; EMBRACE, Epidemiological Study of *BRCA1* and *BRCA2* Mutation Carriers; IBIS1, International Breast Cancer Intervention Study; MARIBS, Magnetic Resonance Imaging for Breast Screening; POSH, Prospective Study of Outcomes in Sporadic Versus Hereditary Breast Cancer; RAZOR, Raloxifene and Zoladex Research Study; UKCCCR, UK Coordinating Committee on Cancer Research; UKFOCCS, UK Familial Ovarian Cancer Screening Study.

But before we proceed, we need to comment upon the homogeneity of the data, which was such that the views expressed by our interviewees did not appear to be influenced by age, gender, education or any of the other personal variables described above, nor were they influenced in any obvious or systematic way by previous experiences of, or the time elapsed since, research participation. In what follows, interviewees are referred to using their study number.

Accounting for participation: personal framing

P124: I think my own attitude towards research for me is purely selfish. It's what I feel I can get out of it, as much as anything ... I think people will take part in research if it affects them personally. Because I think they feel being part of research they feel they will probably get better clinical care. (*EPI 2 years, REG 2 years*)¹

The majority of interviewees, like P124, offered personally motivated reasons for their research participation at some point in their interview. Many of those who had been involved in clinical and DNA research said that they had participated in order to obtain a diagnosis, treatment or surveillance. For example, P149 explained that her participation in the MARIBS study was motivated by the thought that she could access a more accurate screening method (MRI) that might detect cancers earlier than *x* ray mammography:

P149: [I]f there had been anything found I'm pretty sure I would have been given the results. And that's what I was led to believe anyway. That's how I felt about it. So you could say it wasn't for purely unselfish reasons to take part in that screening, because it meant that anything that I had might have been picked up early as a result of it. (*DNA 8 years, REG 4 years, CR 6 years*)

Many interviewees associated research participation with receiving a higher standard of care, and some observed that research was often marketed in this way, with information focusing upon the potential benefits of participation rather than the risks. For example, P142 described how she, and other members of her family, had actually been "encouraged" to take part in an observational ovarian screening study for high-risk women (UKFOCCS) by the promise of therapeutic benefits:

P142: [T]he letters that came out indicated that ultrasound and CA125 were quite positive ways to check for ovarian cancer and although all the families were told it was a study, we were told that there was a benefit to us, that there was not a certainty but a good likelihood that if we were unlucky enough to develop ovarian cancer, there was a very good chance of it being picked up early because we were actually on the research study. (*CR 4 and 6 years, REG 4 and 7 years, EPI 4 years*)

Despite expressing some scepticism about the ways in which UKFOCCS had initially been presented, she went on to describe how her research participation had been clinically beneficial because the research screening had identified some gynaecological problems that would have not been diagnosed as quickly if she had not been screened in the study.

While many interviewees admitted to participating in research to gain direct clinical benefits, for some, the benefits, although perceived as therapeutic, were not necessarily clinical. For example, P115 explained that one of her reasons for participating in the present study was that it gave her the opportunity to talk about her cancer to a neutral third party:

Interviewer: Would that be one of the reasons you'd enter research, because you felt you'd be getting better treatment?
P115: No. I've just entered it because I thought it would be a chance to voice my opinions and speak to someone. And it's like I said, you can't really talk, even to friends and family. (*PS 0 years*)

Likewise, P151 acknowledged that in addition to the potential physical benefits of accessing tamoxifen, her participation in the IBIS trial also had some psychological benefits, as it made her feel as if she were proactively managing her risks of cancer:

P151: It was a mental benefit because you think, oh yes, I'm actually not sitting back and thinking, oh dear, you know, this is terrible. I'm trying to do something about it. (*CR 9 years, DNA 5 years, REG 2 years*)

These data suggest that when deciding to participate in research, individuals attend to the nature of the research procedures themselves and weigh up their associated benefits to see what, if anything, they might gain from participation. Thus, as many noted, participation is at least partially motivated by "selfish" (P124, P149) reasons. The idea that research participation is fuelled, at least in part, by the impact of the research upon themselves is also reflected in the ways interviewees accounted for their (potential) refusal of research invitations. A number of interviewees claimed they were risk averse and said that while they might take part in molecular, psychosocial, epidemiological and even some types of some clinical research, they would be unlikely to take part in clinical

¹ The types of research that interviewees had participated in and the time elapsed since recruitment to different research projects are indicated after each quote.

drug trials because they did not want to expose themselves to the risks associated with ingesting unknown or untested substances:

P148: I wouldn't want to have to take drugs, really. I'm lucky in that I don't have to, which is, it's naughty really because somebody's got to try these things, haven't they! ... I think, if I hadn't had the mastectomies and there was a chance of still getting it, maybe I would think about doing a trial. But because, hopefully, it's gone I don't know if I'd want to be a guinea pig for new drugs. (*DNA 8 years, REG 4 years, EPI 4 and 7 years*)

While many commented that they should be prepared to run these risks and be "a guinea pig" (P117: PS 2 and 3 years), because, as P148 commented, "somebody's got to try these things", they also said they would only be prepared to be that altruistic "somebody" if there was no further hope for themselves or they had exhausted the available treatment options:

P146: I don't want to mess around with my body anymore now, but if it [cancer] came back then I would be quite happy to take part in a drugs trial if it meant a possible cure. (*DNA 1 and 9 years, REG 5 years, EPI 7 years*)

It would appear that even the most risk averse of our interviewees would be prepared to run the risks associated with research if they had nothing to lose—that is, if there were no other treatment options on offer and/or the research offered them the opportunity of personal benefits. However, while some interviewees said that they had participated in research for purely "selfish" (P124) or "not unselfish" (P149) reasons, to gain some therapeutic benefit, and others would refuse to participate in risky research, this does not mean that our interviewees were not motivated to help others. As the next section shows, their accounts were also peppered with altruistic explanations for current, future and past research participation.

Accounting for participation: social framing

P148: I don't think it's [research participation] helped me any at all because I haven't really needed anything done ... so, I've just always looked on it as it's research for somebody. I haven't thought of it as specifically helping me, because I'm not under any doctors or anything. So, I just feel I don't really medically, I don't really need any help, so I'm just quite happy to do this research programme and that's it really. (*DNA 8 years, REG 4 years, EPI 4 and 6 years*)

When reflecting upon their motivations for their research participation a number of interviewees, like P148, said that they had taken part with the intention of helping unspecified others, or society more generally. However, very few constructed participation as purely motivated by the promise of future gains for unknown others, for it was more frequently framed as a form of exchange in which the potential or actual benefits for themselves and others were counterbalanced. In some cases research participation was described as motivated by what Canvin and Jacoby call "weak altruism", namely, instances in which individuals are "happy to help others but only where they could also help themselves".¹⁷ As P123 notes, although he had "selfish" motives for his participation in an epidemiological study, he also recognised that it might benefit others:

P123: I filled in the forms, because to my mind, if it didn't help me, it's going to help somebody else, isn't it? ... it might be

selfish, but in a way, if they are testing my blood, they are finding out if I've got anything in it, and they are helping me as well as other people. If my tests help other people, well, that's good, because it's not only helping them, it's helping me as well. So it's twofold isn't it? Yes, you're getting back what you're putting in, really. (*REG 1 year, EPI 7 years*)

Others constructed their research participation as inspired by a form of reciprocal altruism:⁸

P134: I think it was because you just feel so lucky that you've had all this, the benefits of what's been offered you, and you sort of kind of think, well, if this is going to help, then it's sort of a little bit of—you're giving a little bit back. (*CR 3 years*)

Likewise, P130, who had been on the CAPP2 trial for a number of years, said that he had been partially motivated by a desire to repay the clinic staff for the help he had received:

P130: [Y]ou wanted to help in some way because, they helped me. You know, if it hadn't been for the help I'd got, I wouldn't be sat here and you wouldn't be sat there. So I don't think I felt obligated, I wanted to do it! And I was happy to do it. Apart from the [daily intervention] I was happy to continue doing it and we just kept on and on and on. (*CR 7 years*)

Research participation was seen as a way of paying back the clinical community, for their clinical care—care that, some acknowledged, was only available now because of the altruistic gestures of former participants. As P126b (CR 4 years, EPI 0, 3 and 4 years, PS 9 and 8 years) said, "If it wasn't for people that donated bits and pieces or whatever ...". Similarly, P103 (CR 4 and 5 years) said that she felt she had a duty to participate in research because "I've been very lucky, and a lot of that has been down to trials and genetics and all that sort of thing. So I just feel that if you can help, you should."

Research participation was seen as involving donation: the giving of time, information, blood, tissue or one's body. As P149 said about her participation in this study, "because anything anybody can say to help, although I don't think I've got anything to say that would help. But what's an hour of my time?" For some, taking part in research involved a small amount of time (P149) or a one-off blood donation and was seen as not requiring too much effort.¹⁵⁻¹⁷

P126: So that was how I became involved and then she asked me for a blood test which we didn't really know what it was for at the time. But blood tests don't bother me so, and since then I have entered anything they have asked because I firmly believe that everything that I can do maybe will help my granddaughters because their chance is 50/50 like us. (*DNA 11 years, CR 2 years, REG 4 years, EPI 3 and 4 years*)

While many were prepared to participate if participation was effortless and risk-free, some, like P109, acknowledged that such considerations were not entirely altruistic and could be interpreted as "selfish" motivations:

P109: [I]t's not something I feel pressurised about because I don't feel I have to get it right or wrong, because it's not going to actually have that much bearing on me personally, which probably sounds a bit selfish, but, if you know what I mean, there's no pressure on me if I don't answer your questions right, ... I've got the time and I feel fine then fine, I'll do it. If I haven't, if I was your average Joe that worked nine-to-five and blah-blah-blah, I'd say "I wouldn't be putting myself out." (*PS 2 and 3 years*)

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Others experienced their participation as more onerous. For example, P144 (CR 3 years, REG 3 years), a UKFOCSS participant, did not resent the ongoing commitment or the time involved, but regarded going for blood serum testing three times a year as a “real pain”. However, the economic (P142) or other sacrifices (P130, P144) that interviewees had made were frequently justified by the returns:

P142: At times it's [research participation] been a little bit tedious you know the travelling back and forwards and the cost but over all I think it's an important thing to do and as I say all knowledge is good and the more work is done over the whole world the more information can be done about people who suffer from these types of cancers. (CR 4 and 6 years, REG 4 and 7 years, EPI 4 years)

Like P142, many interviewees observed that they were willing to make these donations because they believed that research was necessary to progress our understanding of genetics or cancer. In relation to this, many commented that they had a duty to participate to help bring about scientific advances so that future generations of society would have access to improved treatment. As P114 (PS 2 and 3 years) said about research participation, “It's got to be done, it's got to be done, really. I'm taking a long-term view. We want to get this right for the next generation, don't we?” Research participation was thus framed as a way of behaving as a responsible citizen,²⁰ as enabling one to fulfil social obligations to future persons:

P147: I do feel like it's part of the jigsaw puzzle and I'm part of that and it's important and I have a responsibility. Now I've got the faulty gene I don't just feel for myself I feel this is about others in the future and I do feel quite responsible about that. (CR 5 years, REG 3 years, EPI 7 years)

Indeed, some interviewees observed that the advancement of science and development of future treatment or services was so important that one should be prepared to take risks that otherwise might be rejected:

P128: But I am happy to go along with the element of risk. You can't advance technology or chemistry, human chemistry without an element of risk anyway, can you? (CR 6 years, REG 2 years)

But those who were prepared to expose themselves to disproportionate risks or inconvenience for the greater good, like P128, were in the minority, for, as noted earlier, there was some indication that interviewees' motivations to participate in research were tempered by their perceptions of the risk–benefit ratio.

In summary, all the interviewees said they were prepared to take part in research that offered them no (direct or obvious) personal benefits and went on to describe some of the conditions for altruistic research participation. These included: the nature of the risks, the availability of clinical care, their health status and finally, as we will see, who in particular might benefit from their research participation.

Accounting for participation: familial framing

Even though most interviewees said that their research participation was motivated by a desire to help others, these expressions of altruism were frequently tempered by the recognition that their participation might directly benefit those they cared about, namely their biological kin:

P126: I have entered anything they have asked because I firmly believe that everything that I can do maybe will help my granddaughters because their chance is 50/50 like us ... I want my granddaughters to be alright. And every time you do it [participate in research] it's a step nearer perhaps isn't it? And of course you have got a terrible guilt ... I have of giving it [mutation] to ... (DNA 11 years, CR 2 years, REG 4 years, EPI 3 and 4 years)

Thus, while many interviewees said that they were prepared to behave in an altruistic manner and run risks for others' benefit, most acknowledged that this was not always totally selfless behaviour, because on many occasions these others were significant others, people that they cared about or cared for—their relatives:

P110: My personal motivations are my son. My son has VHL and ... I'd like him to grow up and there'd be some kind of cure for it, so. But beyond that, it's just a belief that there should be research and um, if it's possible to do, then do it. (PS 2 and 3 years)

Most interviewees said that they had been/were willing to participate in research because it might directly help current children, grandchildren or siblings or future family members.

P142: Obviously there is the positive scientific motivation that all knowledge really is good knowledge. And it's better to have knowledge, then there is obviously the big positive for my children, that if the research brings up ideas, or deductions or new ways of clinically testing people before they have gone down with cancer, you know it gives everybody in the future a better opportunity. (CR 4 and 6 years, REG 4 and 7 years, EPI 4 years)

In this sense, research participation was not seen as motivated by “pure” altruism, in the sense that it was perceived as an “unfettered donation”,⁸ because, as many interviewees commented, it was undertaken with the expectation that it might benefit those that they had an interest in protecting:

P104: I mean, it's [research participation] sort of for selfish reasons at the back of my mind, I've got two daughters so anything that can be done to help the understanding of what's going on will help them in the long term, won't it. (CR 5 years, REG 5 years, EPI 4 years)

The idea that family interests are coterminous with one's own interests was expressed in many interviews:

Interviewer: And do you think, is there any particular types of research that you wouldn't consider taking part in if you were asked?

P105: No, I don't. If it could find a way of stopping this [cancer] happening, then obviously—we've got a big family of girls, so if it is something in our family, it would be great to find a way of preventing it. So I'm game for anything ... when it's like in the family like that, I think really it's in your best interests to say yes, right-ho, whatever. (CR 3 years)

Although research participation that helps others is normally seen as motivated by altruism, in certain instances our interviewees constructed this “altruistic” behaviour as “selfish” (eg, P104, P137). P131 reflected upon his varying motivations for participation in CAPP2, acknowledging that a more selfish agenda of helping his family exists alongside his more altruistic motives of helping others with the disease more generally:

P131: Primarily because I felt that if I was helping other people, and if there was likely to be something that—not necessarily a cure, but something that would relieve the symptoms or the

possibilities of bowel cancer in other people, then I thought I—you know, I was fortunate enough to have survived it, and fortunate enough to be in a position to take part and help other people. But obviously, in a selfish way, my own children and my grandchildren, if my own bloodline is likely or possibly—you know? (CR 3 years)

It can be argued that participation in research that benefits one's family is constructed as selfish because it indirectly benefits oneself, in so far as it allows one to fulfil one's familial obligations of care.²¹ For example, P137 said she would put her self at risk by participating in more intrusive research, but only if it enabled her to "save" or "help" those she cared for:

P137: If you said you wanted to test an anticancer drug on me [laughter] or something, unfortunately I would be selfish here, and it would have to be something that I could feel somebody close, my daughter, or relatives could benefit if I said yes, that could save, or that could help then I would do it but otherwise I am afraid ... (CR 6 and 8 years, REG 2 years)

In presenting themselves as someone who is "game for anything" (P105) and who will do what they can, within limits, to protect those they are related to, our participants were thus able to construct themselves as responsible and caring individuals.

Framing research participation: a dynamic process

Although we have presented the motives for research participation separately in this analysis, even the most cursory reading of these data demonstrates that these motivations coexist in complex, interrelated ways within the interviews. As is illustrated in P151's account of her participation in the IBIS trial, it is apparent that the various motivational framings for participation stand in a dynamic relationship, in so far as they impact upon each other and metamorphose in the telling:

P151: [I] would say I think it's more for other people. But specifically with the tamoxifen, I mean obviously if I hadn't been on tamoxifen, it [research participation] would have been of no benefit to me at all.

Interviewer: Your decision to be involved in IBIS, what was behind that?

P151: Well, once I knew about it, the first thought in my mind was my daughter. I thought, "Right, if I can do something, positive, rather than just sit round and do nothing." And also of course it was selfish as well, because I thought, "Well, I might get to have some tamoxifen and the extra care" ... So it was both really, for me and for society in general. (CR 9 years, DNA 5 years, REG 2 years)

Like P151, our interviewees typically said that they had taken, or would take, part in research for many reasons, one of which might be to gain personal therapeutic benefits—access to treatment (personal direct gain)—at the same time this participation may be acknowledged as adding to the sum of knowledge about treatment that may benefit future generations of patients (social direct gain), and the participant's family (direct familial gain), which, in turn, benefits oneself as it enables one to fulfil one's social obligations of citizenship and one's familial obligations of care (indirect personal gain). In other words, the data suggest that the motives underlying research participation are constructed as existing in an interdependent relationship that can be represented as interleaved and interlocking. Like the cogs depicted in fig 1, drawing upon any one motive to account for one's behaviour in this context is not sufficient, for each motive would appear to impact upon, alter and modify others in a recursive or dynamic fashion.

DISCUSSION

This study sought to determine research participants' motivations for taking part in a range of different types of research projects in the UK related to cancer genetics. Our interviewees framed the motives underlying research participation in a variety of ways and talked about the benefits for themselves, their families and the wider society. Thus, on one level, our findings echo those reported in earlier studies, which suggest that research participation is fuelled by altruistic as well as more personal motives.^{11–13 22} However, it was also noted that individuals' motivations for research participation are often difficult to describe as either self- or other-oriented, for the different framings coexist in a number of complex and dynamic ways within these interviews; indeed, the interviewees repeatedly juxtaposed these different framings when discussing their former and future research participation. The fact that our interviewees reported different motives for research participation in these interviews without any apparent tension or contradiction suggests that the presentation of the motives underlying research participation as dichotomous, as reflecting the oppositional categories of self versus other (see discussion of literature in 17) is a simplification and a methodological or analytical artifice.

Following Canvin and Jacoby¹⁷ and Haimes and Whong-Barr,¹⁵ we speculated that the degree to which individuals might draw on altruism to account for their (hypothetical) research participation may be related to the risk–benefit ratio, the amount of effort involved in particular projects and the individual's personal situation. This seems to have been borne out by the data indicating that when citing altruism as a motive our interviewees appeared to take into account a combination of personal circumstances—primarily health status—and the particular requirements of the research. In other words, our interviewees regard altruism as context-dependent and construct it as a particularised rather than a general concept.

Thus, although most of our interviewees claimed they would, or indeed should, participate in research to help future patients including their family, in the main they said that they were only prepared to engage in these activities if this did not put their health needlessly at risk,^{17 22 23} if they might also benefit or if they had exhausted all therapeutic options. These findings recapitulate those of an earlier study that found respondents favour recruitment (without their consent) to hypothetical research studies that involve experimental drugs that their doctor thinks "might help them" rather than to placebo-based randomised controlled trials and also rate the less invasive

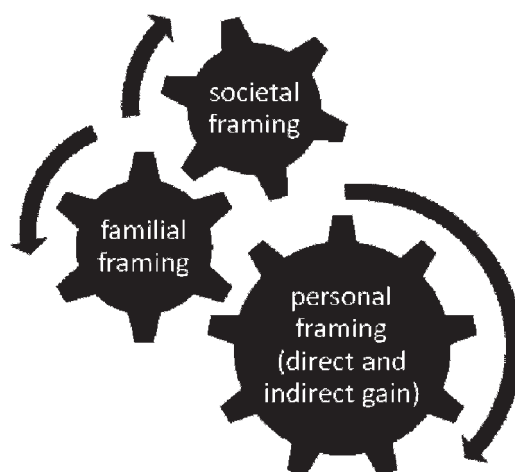


Figure 1 Framing motives for research participation.

Research ethics

interventions as more acceptable.²⁴ Dixon-Woods and colleagues similarly observed that while the parents in their study voiced communitarian motives for research participation, they were willing to donate their child's tissue for research only if they perceived there was no risk to their child.^{2 23} Our data similarly imply that there are limits to research participants' altruism—things they will not do or risks they will not take to help others—suggesting, as Haimes and Whong-Barr contend, that the truly altruistic participant who will run any number of risks and expend a large amount of effort purely for others' benefit is, indeed, very rare.¹⁵

The fact that our interviewees said they would be less likely to participate in drug trials or invasive research implies that they perceive the epidemiological, molecular and psychosocial research that takes place in cancer genetics clinics as less risky. Alternatively, they may be less aware of the psychosocial and economic risks—the emotional sequelae and potential disruption of family relationships that can be associated with these types of research.^{11 14} Indeed, research with those who undergo clinical genetic testing suggests they are often unaware of the emotional sequelae and potential impact on family relationships.^{25 21}

One of the problems with the above interpretation of the data is that it constructs research participation, in general, and altruism, in particular, as individualised behaviour and underplays the fact that our interviewees are social actors who exist within a network of social relations. Dixon-Woods and Tarrant²³ have recently argued that we need to see research as social action, involving cooperation between researchers and participants. They argue that cooperative research is a form of “joint action”—a dynamic form of collaborative social interaction, in which the actions of both parties and the relationships that exist, or are created, between them are fundamentally important. Constructing research activities in this way has the effect of redirecting our focus upon the relationships that exist between the different parties—researchers and participants, participants and their families and participants and the wider society.

Using data collected in three different studies, Dixon-Woods and Tarrant²³ observed that interviewees consistently emphasise “the moral character of research participation” acknowledging that this activity contributes to the common good to which all responsible people should contribute (see also Harris²⁶). The idea that researchers and participants are engaged in a cooperative relationship was supported in this study by the observation that many of our interviewees talked about their research participation in terms of reciprocal altruism—as paying back former participants for their participation in earlier studies or the clinical staff who recruited or cared for them. This reiterates Titmuss's observations that blood donors often describe their donations as repayment for past transfusions⁸ and also has been described by Dixon-Woods and colleagues in their recent study of tissue donation.²

Many of our interviewees also talked about how they wanted to contribute to discoveries in cancer/genetics research, again suggesting that they regarded their research participation as a cooperative venture, one of the aims of which is to contribute to knowledge^{17 22} and the advancement of science or of treatment.¹⁰ These data, therefore, demonstrate that our interviewees were clearly aware of the epistemological basis of research activities. Thus, while they may see their research participation as motivated by a number of disparate motives, including a desire to gain therapeutic benefits,¹³ the data suggest it is not primarily sustained by a therapeutic misconception^{27 28} that is characterised by Henderson and colleagues as a failure to understand “that the defining purpose of clinical research is to produce generalisable knowledge” (P4).²⁹

Our data also indicate that our interviewees are well aware of “the moral character of research participation”. Dixon-Woods and Tarrant warn, however, that one should be wary of interpreting accounts of research participation in this way, pointing out that accounts that describe participation in medical research as serving the public good are often, among other things, “evidence of the more general attempt to defend moral character found in most accounts of action” (p4).²³ To some extent we agree, and acknowledge that both the research design and the subject matter of these interviews may have encouraged our interviewees to present themselves as morally accountable for their actions.¹⁵ However, we argue that we should not just dismiss this type of account as a methodological artifact. By describing the conflicting and often complex motivations underlying their research participation, our interviewees provided us with important insight into how morality is negotiated and illuminated some of the complexities involved in constructing oneself as a moral being in the context of what is rapidly becoming a research culture.

To illustrate, nearly 20% of the interviewees referred to their research participation as “selfish”, either because it directly benefited themselves, for example, provided access to treatment (P151) and did not expose them to any form of risk (P109), or, more frequently, because it provided some form of indirect personal gain, for example, it might benefit their family (P123, P104). Although we might expect that actions taken to benefit oneself or to avoid exposure to risk would be described as selfish, those that are undertaken to protect and benefit one's family or others, especially those involving a degree of burden or risk, would normally be viewed as laudable and selfless behaviour—as examples of altruism. Thus, it is interesting to note that some of our interviewees regarded behaviour that benefits others—family members—as motivated by a degree of self-interest, suggesting that they see themselves as falling short of some ideal model of participation—a model in which research participation is seen as arising from some form of unadulterated altruism. While the interviewees' recourse to a discourse of selfishness to account for their behaviour in these instances could be read as some form of an apology, it could equally be seen as evidence that altruism is more ethically complex than even Titmuss has suggested.⁸

We speculated in our introduction that altruism may be emphasised to a greater extent when participating in certain types of genetics-related research. Previous research indicates that family relationships play a major role in decision-making about clinical genetic testing.^{21 25} There is evidence that many men and women attend cancer genetic counselling and proceed to DNA testing primarily to gain a diagnosis that family members can use to obtain testing for themselves.^{25 21} While such actions can clearly be described as altruistic, it has been observed that they also benefit the individual by allowing them to fulfil their familial obligations of care.^{25 21} It can be argued that participation in genetics-related research, an activity that, by definition, may (directly) benefit future generations of the participants' family, is seen in the same way. At one and the same time, research participation is altruistic (one's actions are undertaken to benefit others) and can be seen as selfish (one's actions indirectly benefit oneself). Such observations suggest that we may need to rethink the concept of altruism and what Dixon-Woods and Tarrant²³ refer to as the “moral character of research participation”. Also, as we noted earlier, we need to recognise that when it comes to accounting for research participation we can no longer regard altruism and selfishness as incompatible or oppositional concepts. Indeed, it would

appear that research participation is experienced as a more ethically contentious activity than has heretofore been assumed.

LIMITATIONS

Finally, we need to consider the importance of personal experience in these accounts. All our interviewees were at increased risk of cancer, but healthy, when interviewed. However, the extent to which their accounts were based on personal experiences varied: some had taken part in a wide variety of projects, but others had not and so could only speculate about what they might do in a given situation. Thus, the data consist of two types of account: general accounts, in which research participation is framed as a hypothetical scenario, and more particularised accounts, constructed from real-life experiences. We would argue that juxtaposing these in the above analysis is acceptable, not least because both are underpinned by similar (ethical) reasoning, but also because accounts based upon previous experiences, like hypothetical accounts, are informed by the social context in which they are produced. As noted above, as is the case in all interview studies, our interviewees were subject to a moral pressure to “perform” well in the interview and present self in a favourable light. In this respect, accounts that purport to be based upon personal experiences could be, better, interpreted as *post hoc* rationalisations of behaviour³⁰ rather than reports of “actual” motives underlying previous research participation. Similarly, when engaging in speculation about how they might behave when faced with research invitations in the future, it is possible that many of our interviewees sought to present themselves as responsible individuals.

CONCLUSIONS AND IMPLICATIONS

This study suggests that participation in research relating to cancer genetics is seen as an activity that serves many disparate purposes or interests and that benefits a range of people. Our data indicate that research participation is influenced by the hope of personal gain; by a desire to help researchers or future patients and to repay former participants and clinical staff; and by the wish to advance science and to help members of one's family or the wider society. It would appear that participants' motives are less than straightforward and involve much more than simply weighing up the risks and benefits to self or simply balancing altruistic and selfish motivations. Indeed, it can be argued that research participants see themselves as positioned in a complex network of relationships in which their actions are tied to others in the past and future. Thus, while the process of consenting to participate in research projects in cancer genetics can be viewed as an exercise of individual agency—for, after all, it is the individual who signs the consent form, allows blood to be drawn for DNA analysis, undergoes MRI screening, takes trial medications or fills in a questionnaire—the motivations underlying such behaviour can be seen as multi-faceted and complex and, according to these interviewees, and as others have observed,²⁹ are also profoundly social in origin.

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